

The Infected Blood Public Inquiry NEWSLETTER



THE
HAEMOPHILIA
SOCIETY

A summary of inquiry hearings

Campaigners have been the focus of this week's hearings. Bruce Norval, an "expert patient" infected with hep C as a child as a result of his haemophilia B treatment, presented research about the role of military vaccines and their history of transferring viruses. He said haemophiliacs were "useful material" to researchers. What doctors were really interested in, he said, was "what we catch".

Jason Evans, whose dad Jonathan died aged 31 after being co-infected as a result of treatment for his haemophilia, described how this loss had "blanketed" his life. He set up the Factor 8 campaign group in the wake of the Penrose Report, which was criticised as a whitewash. He uses Freedom of Information requests to track down government documents. He was critical of the process in which civil servants decided not

to release information and then looked for a reason to justify it. He urged government to "err on the side of transparency".

Robert James, a patient activist and former chair of the Birchgrove group, was critical of haemophilia consultants' lack of knowledge in the 80s and 90s. He decided to educate himself about his HIV and hep C to ensure he and others got the best treatment.

Inquiry news in focus: devolution

The leaders of Haemophilia Wales, Scotland and NI described how their relationship with their devolved governments had impacted on their campaigning and, in some cases, had been a key factor in making progress. Bill Wright, chair of Haemophilia Scotland began his evidence by saying: "I cannot emphasise enough the importance of devolution in this whole story." The Ross Report into financial and other support for victims of contaminated blood in 2003 was the start of Scotland starting to look differently at the issue, culminating with the Penrose Inquiry which Bill described as "utterly exhausting". Lynne Kelly, chair of Haemophilia Wales, described setting up a cross-party group on haemophilia and contaminated blood in the Welsh Parliament and the close collaboration the group has with clinicians as well as politicians. In 2017 the Welsh Parliament voted unanimously in favour of a public inquiry which was a major break-through, she said. Nigel Hamilton, chair of Haemophilia NI, which was set up in 2017, said the three-year period when the NI Executive collapsed made relationships with Westminster MPs more important in its campaigning work.

Quotes of the week

"We are the people who take these drugs...and our voice has to be...at least of an equal value with that of clinicians when we are deciding about what happens to us." Robert James

"This [HIV and hep C infections] isn't an unexpected outcome. This is the expected outcome. I think the only accident was that we lived long enough to complain about it." Bruce Norval

"I think our campaigning is our way of trying to fix it, fooling ourselves that if we win, somehow everything is okay again. But the reality is that for too many of us, there can never be a win for this campaign." Jason Evans

"This campaign has truly been fought on the shoulders of giants. They fought the lack of transparency, accountability and willingness to engage for over 30 years and we will not forget their perseverance."

Lynne Kelly, Haemophilia Wales

"It was a damned insult...This is the wrong way to do government. You have to engage with people, you don't just throw money at people."

Bill Wright on David Cameron's announcement of £25m for victims of the contaminated blood scandal in 2015 after the Penrose Inquiry

"I felt anger..It had not served the people..perhaps it served the government, but it didn't serve anybody else. After Penrose there was a great feeling that we'd just been beaten down. "

Simon Hamilton on the Penrose Inquiry